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Abstract

Children with profound and multiple learning disabilities (PMLD) are said to experience severe congenital impairments to consciousness and cognition stemming from neurological damage. Such children are understood as operating at the pre-verbal stages of development, and research in the field typically draws conceptual resources from psychology to devise educational interventions and assessment tools. Criticism has been levelled at studies which treat children with PMLD as objects of research rather than subjects to be consulted. Proponents of the latter view have attempted to redress the situation by exploring how personal experiences can be gleaned through adapted qualitative methods. Debate about methodology in the PMLD field tends to coalesce around these individualist polemics: children with PMLD are either positioned as incompetent and lacking voice; or researchers are positioned as lacking the appropriate tools to gain access to such voice.

This paper offers an alternative position to the individualism of post-positivist/constructivist approaches, identifying the need for a critical and participatory approach which sees knowledge about children with PMLD as situated and co-constructed through regular and longitudinal interaction between the researcher, children with PMLD, and significant others. Context to this argument is provided by exploring the application of this approach to an inclusive education research project for a child with PMLD.

Key words

Methodology, PMLD, profound and multiple learning disabilities, interpretivism, constructivism, participatory research

Introduction

This paper describes an innovative approach to conducting research with children who have the label “profound and multiple learning disabilities” (PMLD). It does so in order to illuminate how researchers can move beyond the individualism at the heart of post-positivist and constructivist methodologies employed in the PMLD field. The term “individualism” refers to the monadic nature of these research approaches, meaning that children with PMLD are understood in abstraction from the everyday situations and relationships that they live through. Individualism locates voices “in” children and leads researchers to the view that either children with PMLD are too cognitively impaired to speak for themselves (e.g. they lack a point of view and are incapable of being consulted), or researchers lack the skills and methods to “listen” to children with PMLD. The approach described in this paper contributes to the debate by offering a different perspective. It is helpful to conceptualise voice not as something indivisible and located in children, but as something which can be expressed in action towards the physical and social worlds, and hence is contingent upon the relationships people develop over time and across contexts. The richly interpretivist approach presented explores this dimension of voice through relational forms of knowing, longitudinal qualitative observations, and informal but on-going dialogue over the meaning of actions over time. The paper proposes that there is a pressing need for methodological innovation in the PMLD field which allows deeper understandings of lived experiences and agency of children with PMLD. However, this requires a more complex understanding of both *what* we listen to and *how* we listen.

Context to the approach presented in this paper is provided by describing its application during the first author’s ESRC-funded doctoral research¹ (Simmons, 2010) concerned with the educational inclusion of children with PMLD. The findings of this project have been published in more detail elsewhere (e.g. Simmons and Watson 2014).

Introducing Sam²

The research from which this paper is drawn involved a nine-year-old boy with PMLD called Sam, who lived with his family in South-West England. Sam was diagnosed with cerebral palsy

¹ Supervised by Dr Phil Bayliss and Dr Debbie Watson at the Graduate School of Education, University of Exeter (UK).

² At the request of Sam’s parents we continue to use his real name.

as well as auditory and visual impairments (the extent of these impairments was being investigated by clinicians at the time of the research). Sam was described by his special school teacher as operating at a pre-intentional level of communication. He attended a special school four days a week and was placed in a special care class for children with profound and complex disabilities. He also spent one day a week in a mainstream class at his local primary school where he was aided by two learning support assistants (LSAs).

The research was concerned with whether or not Sam's different schools provided different opportunities for engagement (particularly social engagement), and how this impacted upon his development and learning. Conceptual resources were drawn from Trevarthen and Aitken (2001) and the focus was on whether Sam's different social milieus supported primary intersubjectivity and emergent secondary intersubjectivity. Behaviour state research (Foreman et al., 2004) was also utilised in order to explore whether Sam's levels of alertness could be linked to different social contexts. Given the individualised behaviours of children with PMLD (e.g. the ways in which their mobility, sensory and cognitive differences lead to personalised forms of action) a methodology was devised based on explicit forms of interpretation. The ambition was to understand the meaning of Sam's individualised actions and this involved learning from Sam and negotiating meaning with significant others (such as his LSAs and teachers).

Defining "PMLD"

PMLD is a label given to people (in this case, children) who are said to experience the severest of impairments to cognition resulting in significant developmental delay (Scope, 2013). The abilities of such children are often compared to those of the neonate or infant insofar as children with PMLD are described as operating at the preverbal stages of development (Coupe O'Kane and Goldbart, 1998). Consequently, descriptors are used in the literature to indicate that children with PMLD typically fail to reach particular developmental milestones that some associate with later infancy. Children with PMLD are understood as being: pre-volitional (lack free will or agency and cannot move with intent) (Farrell, 2004); pre-contingency aware (do not show awareness of cause-effect relationships) (Ware, 2003); pre-intersubjective (do not represent other people as subjects "like me", and cannot differentiate between subject and object); pre-symbolic or pre-intentional (do not intentionally communicate meaning to others) (Coupe O'Kane and Goldbart, 1998); stereotypic in behaviour (displaying reflexive, non-

volitional behaviour) (Tang et al., 2003), and at risk of living in a world of confusion (Cartwright & Wind-Cowie, 2005).

In addition to profoundly delayed cognitive development, children with PMLD are also said to be prone to physical impairments (Neilson et al., 2000), sensory impairments (Vlaskamp & Cuppen-Fontaine, 2007), mental health difficulties (Fergusson et al., 2008), and complex medical conditions (Pawlyn & Carnaby, 2009). They may also engage in challenging or self-injurious behaviour (Denis et al., 2011). Thus, children with PMLD are described as being dependent on others for the most rudimentary care needs and deemed to require a lifetime of support (Tadema & Vlaskamp, 2010). With optimal intervention it is hoped that children with PMLD will make some progress through the preverbal stages of development.

The definition of “PMLD” given above is derived from a review of published research literature and results in a deficit-account of children described as having PMLD. In this paper we seek to address the situation by suggesting an alternative methodology which has the potential to allow richer understandings of children with PMLD to emerge.

Research in the PMLD field

Historically, researchers in the PMLD field have drawn conceptual resources from psychology, in particular behaviourism and cognitivism, to devise assessment tools and intervention strategies. Behaviourism is an approach concerned with the scientific study of observable behaviour. Central to behaviourism is the idea of learning as conditioning. Conditioning here is construed as an unconscious or automatic form of learning that underlies the acquisition of behaviour (Gregory and Zangwill, 1987). A wealth of international research has been published exploring the efficacy of behaviourist training programmes to develop functional or adaptive skills in people with PMLD. These skills are defined as behaviours which allow people to care for themselves and engage with the world (Reid et al., 1991). Training programmes are usually guided by operant conditioning theory, and it is hoped that the presentation of a stimulus each time a discrete behaviour is performed will increase the likelihood of that behaviour reoccurring (Saunders et al., 2003). Much research has been published documenting strategies for identifying stimuli to act as reinforcers (Tullis et al., 2011), and reinforcers are often used to increase the occurrence of behaviours such as microswitch-pressing (Mechling, 2006). The

idea being that by learning to press microswitches, people with PMLD may master a level of control over their environment.

An alternative to the behaviourist approach is one that attempts to develop social cognition and symbolic communication in people with PMLD. This cognitivist approach is not concerned with controlling discrete behaviours through presentation of stimuli. Instead, it fosters the beginnings of social awareness so people with PMLD can begin to engage intentionally with those around them (Coupe O’Kane & Goldbart, 1998). For example, *Intensive Interaction* (Nind & Hewett, 2001) is an intervention that supports the simulation of interactive sequences described in studies of parent–infant communication (such as contingent responding, imitation, and turn-taking). The idea is that infants naturally develop intersubjectivity and communicative intent through preverbal, implicit social transactions with parents. By simulating what occurs between parents and infants, practitioners can engage with people with PMLD on a basic level which may lead to social learning. A different intervention involves constructing contingency-sensitive or *responsive environments* (Ware, 2003) on the basis that if the environment consistently responds to select behaviours; then people with PMLD may discover that they can influence their surroundings—that is, they develop contingency awareness. It is argued that people with PMLD first need to learn that their actions have consequences in the material world before they learn that their actions can also be meaningful to others and thus influence the social world.

Behaviourist and cognitivist approaches are not mutually exclusive and research interests sometimes overlap. For example, research into switch-based training programmes has explored how the presentation of preferred stimuli can lead to the emergence of contingency awareness (Lancioni et al., 2005), and the purpose of some behavioural interventions is to support the development of communication, such as indicating choice (Lancioni, 2007).

Both approaches also share a commitment to the scientific study of behaviour and cognition requiring researchers to adopt an objective stance in relation to the objects (or subjects) of research. From this post-positivist perspective, there is a “real” world external to, or independent of, human experience of the world; the world is “out there” whereas human subjectivity is somehow encased “inside” the human organism. The mind becomes a “mirror of nature” (Rorty, 1979, p. 12), an inner realm in which objects of the external world are reflected or represented resulting in a distance between the knower (in this case, the researcher in the PMLD field) and the known (the child with PMLD).

Critiques and the search for constructivist approaches

Approaches based on an objectivist psychology (above) have long been criticised for not adequately capturing the “voices” and experiences of the people with disabilities. This point was made by Edgerton (1993) over two decades ago:

An outstanding void in existing sociological knowledge of the mentally retarded is a detailed description of the everyday lives of such persons outside of custodial or treatment institutions. Neither the details of their everyday conduct nor their own thoughts and emotions concerning their life circumstances have been documented. (p. 6)

Although Edgerton’s terminology is outdated (“mentally retarded”) the point being made still resonates to this day for children with PMLD as there is a distinct dearth in research detailing their everyday routines and lived experiences (Simmons & Watson, 2014). Instead, research is typically concerned with the efficacy of intervention strategies that aim to change behaviour (sometimes conceptualised in non-volitional terms). Edgerton (1993) not only argued that adequate explanations of behaviour require understandings of subjectivity, but that such understandings are best gleaned by developing intimate knowledge and awareness of the actor through prolonged personal contact.

For many years disability activists and researchers have argued for inclusive methodologies built on principles of equity and social justice which echo the tenets of the social model of disability, whilst challenging incremental perspectives associating the extent of a person’s impairments and their ability to participate in research (Goodley et al., 2004).

Primarily these debates focus on *people* with PMLD as opposed to *children* and this mirrors debates in childhood studies, where researchers have advocated appropriate participatory approaches to engage *all* children in research (Christensen and James, 2008; Punch, 2002). Although such claims often do not specifically relate to disabled children, it is claimed children have been denied rights based on arguments that “they lacked rationality, they lacked competence, they needed protection not autonomy” (Tisdall, 2012, p. 182). Some researchers argue that rights-based approaches are unrealistic on the basis that the label of “PMLD” suggests someone operating at a “pre-intentional level who reacts to an event” (Ware, 2004, p.176). Ware (2004) has argued that this is about expressing a choice or a preference and not a

view as prescribed in rights-based approaches. This arguably reflects a reductionist, post-positivist perspective that denies rights to people with PMLD. Others are more optimistic for the possibilities of research with disabled children in order “to define disability in their terms to allow for the intersection of childhood and disability” (Watson, 2012, p. 199). Questions over the facilitation of “voice” for those with severe disabilities do however remain, with concerns about the representation of disabled children’s voices through researcher-chosen quotes or observations of interactions and of the need for transparency (Abbott, 2012).

Brewster proposes an approach to “accessing views as an ongoing process” (2004, p. 169) rather than a one-off data collection activity, as may be the case with non-disabled participants. This suggests the need for relationships to be made with participants and peers/ family/ carers over an extensive period of time in order to understand the extent to which individuals are able to have their views heard through facilitated approaches (Mitchell, 2010). This is even more the case when we consider children with severe communication difficulties, who are reliant on interpretation of their views and wishes through adult intermediaries (Beresford, 2012). Morris (2003) reported a methodology of “being with” young people who had no language in order to understand their experiences:

Sometimes this took the form of straightforward observation of what was going on in a situation; other times it involved joining in an activity, such as having a meal, or accompanying them on an outing. (p. 345)

Morris’ (2003) experiences challenged some parent, carer and professional perspectives of children who were deemed non-communicative and incomprehensible stating:

...all children and young people—whatever their communication and/or cognitive impairment—have something to communicate. It is up to us to find ways of understanding their views and experiences. (p. 346)

There is insufficient space here to fully review the literature that has attempted to access disabled children’s experiences and preferences³. However, it is important to acknowledge that there are very few studies that claim to access the views of children with PMLD, although disability definitions vary across studies. In one study 6 young people with “profound and complex learning needs” (Whitehurst, 2006, p.55) engaged in a drama project with 23 pupils from a mainstream school and were later interviewed using a combination of photo elicitation

³ See Simmons & Watson (2014) for a more detailed review

methods, Makaton and ‘Talking Mats’⁴ in order to accommodate differences in “student’s capabilities in terms of their expressive and receptive language skills” (*Ibid.*, p. 58). Other studies have utilised participatory observation methods with children with less severe disabilities (Cocks, 2008; Burke, 2012). For example, in the study by Cocks (2008) the data was recorded in naturalistic field notes where she claimed “interaction came out of the general environment rather than being exclusively initiated by the children themselves” (p. 176). Whilst this is an important observation in respect of the ways in which environmental context may influence interactional behaviour, the children in her study were described as having disabilities that were “moderate to severe” (p.166). Regardless of the level of children’s impairments, debates are apparent in the literature about the extent to which the use of child-friendly and creative methods are strategically facilitative in providing access to the views of disabled children, or whether they are part of a broader project enabling the fuller participation of disabled children in the research processes (Beresford, 2012).

Ontological and epistemological reflections

What both the post-positivist approaches and constructivist approaches have in common is an individualist perspective of knowledge, whereby researchers come to know children with PMLD as subjects or objects of research, either through quantitative observational methods or through some sort of adapted system of symbolic communication to allow children with PMLD to “speak for themselves”. Thus, debate about methodology in the PMLD field tends to coalesce around these individualist polemics: children with PMLD are either positioned as incompetent and lacking voice; or researchers are positioned as lacking the appropriate tools to gain access to such voice.

This paper describes the approach used in a project about the “inclusion” of a child with PMLD. The approach went beyond the individualism at the heart of traditional scientific and constructionist approaches and moved closer towards the participatory paradigm emphasising eradication of the researcher-researched binary toward a more equal or democratic relationship of knowledge co-construction. Unlike the constructivist perspective which may involve a researcher employing hermeneutic methodology to deepen understanding of another person’s

⁴ Developed by Cameron, L., Watson, J. & Murphy, J. (2004) Talking Mats: a focus group tool for people with learning disability, *Communication Matters*, 18, 33-35.

experience or knowledge, the participatory approach is less about one person understanding another, and more about two (or more) people working together to achieve greater understanding. Importantly, the participatory paradigm does not privilege either the objective world or subjective world, but reconceptualises the nature of knowledge in relation to both subjectivity and objectivity. Meaning is enacted through the engagement of people in the world, and is not outside the world waiting to be discovered or constructed by the mind. From the perspective of a participatory approach, knowledge for and about people emerges by working “with” people rather than conducting research “on” them, and commonly involves a transformative component insofar as people conduct research to change their local situations and/or challenge approaches to knowledge which position non-dominant groups (such as people with PMLD) as outsiders (Brydon-Miller et al., 2011).

Applying the approach: methods used

Central to the project was the need to develop understandings of the meaning of Sam’s behaviours (e.g. by learning to differentiate between non-volitional reflex behaviour and behaviour which may be indicative of social awareness and intentional communication). Sam’s individualised behavioural repertoire meant this differentiation required acts of interpretation and “coming to know” Sam through processes of familiarisation and engagement with him over extended periods of time. It also required open and reciprocal dialogue with significant others who knew Sam and could share their understandings of his behaviours. The following sections describe the project, which made use of participatory and non-participatory observations, pre-observation focus groups and on-going dialogue with staff and parents. These methods were employed over an academic year. For the first two terms the researcher observed Sam twice a week (once a week in a mainstream class and once a week in a special school class) which totalled approximately forty days of observation. In the third and final term the researcher observed Sam four days in mainstream school and four days in special school.

The study received full ethical approval from the University of Exeter. Informed consent was sought prior to fieldwork from parents and schools. The researcher was introduced to Sam to ascertain whether he was happy to be in the researcher’s presence. In addition to informed consent, on-going consent was also sought from Sam insofar as the research continued as long as Sam was happy to be in the researcher’s presence (something monitored by school staff). The methodology was designed to support authenticity (trust-worthy interpretations) to ensure

that the researcher did not misrepresent Sam. The researcher was not involved in personal care for Sam.

- **Pre-observation focus groups**

Before fieldwork commenced, three focus groups were facilitated with Sam's mum, teaching staff, and others involved in Sam's education and care (referred to as "significant others") in order to learn about Sam (his interests, abilities, methods of communication etc.) from those that knew him intimately. Significant others were able to differentiate between and understand the meaning of subtle differences in Sam's behaviours. For example, Sam's parents and learning support assistants (LSAs) differentiated between various "unhappy" states such as Sam being in pain and Sam being bored or frustrated. If Sam suddenly emitted a high-pitch scream, began to cry and frantically hit his head then this behaviour was said to indicate that he was in pain. By contrast, if the self-directed behaviours (particularly neck-pinching) increased in duration and frequency over time, then it could indicate that Sam was becoming increasingly bored or frustrated. The views of others helped guide the researcher's initial observations by providing a lens through which to understand Sam's behaviour

- **Participatory observation**

Traditionally, researchers in the PMLD field have taken a distant observer role and employed structured observation schedules in order to quantify the rate of behaviours. By contrast, the project described in this paper made use of participatory forms of observation. As the name suggests, participatory observation involves the researcher acting or participating in the lives of those he or she is trying to understand. This involves the researcher immersing himself or herself in the everyday routines and activities of the research subject(s) in order to become intuitively familiar with and get a "feel" for these activities and how people respond to and experience the world around them.

During the project, the researcher engaged in on-going participatory observations by acting as an LSA for Sam once a week in his mainstream school and once a week in his special school. The purpose of participatory observation was to allow for alternative ways of "getting to know Sam" and "being with" (Morris, 2003) him. Interacting with Sam and supporting his learning and development alongside other specialist LSAs allowed access to knowledge about Sam's day (such as his routines, curriculum, responses to different teaching methods and behaviours). Participatory observation helped to develop rapport and trust from the other members of

classroom staff (Cohen, Manion, and Morrison, 2011) and provided opportunities for informal discussions with staff in real time. These conversations emerged naturally as staff provided support and advice to resolve confusion about why Sam was behaving in a particular way, and how best to respond.

In addition, participatory observation provided opportunities to “test” emergent ideas such as exploring whether certain self-directed behaviours (such as Sam slapping the sides of his head with both hands at the same time) were intentionally communicative. For example, it became apparent that in his special school Sam would slap his head in the researcher’s presence (but not in a way which was self-injurious). Sam stopped slapping himself when the researcher was out of view. This was discussed with Sam’s teacher, who had not noticed the behaviour before but theorised that it may be a form of intentional communication, in the sense that Sam was attention seeking.

- **Non-participatory observation (vignettes)**

Non-participatory observation provided opportunities to create data through the writing of vignettes. Vignettes are rich prosaic renderings of observational field-notes about social action. They have a story-like structure and maintain chronological flow. Vignettes are usually restricted to a particular place, time and actor (or group of actors) and vary from a few lines to the length of a chapter (Miles et al., 2014). Erickson (1986) defined the vignette as:

... a vivid portrayal of the conduct of an event of everyday life, in which the sights and sounds of what was being said and done are described in the natural sequence of their occurrence in real time. This moment-to-moment style of description in a narrative vignette gives the reader a sense of being there in the scene (pp. 149-150).

Whenever opportunities emerged for Sam to socially interact, detailed descriptive accounts were recorded of the interaction as it unfolded, with particular attention paid to who initiated the interaction and how, the responses of the participants over time, and contextual variables such as place of interaction and objects used. This included micro-descriptions of Sam’s facial expressions and body movements which were crucial in the early research stages in order to develop a basic understanding of how Sam expressed his emotions (i.e. to differentiate between Sam being happy, unhappy, focused or bored). This entailed writing about where Sam was looking, whether he raised his eyebrows, the shape of his mouth, how his head was tilted, what

his arms and legs were doing, the noises he was making, etc. The following is an example of an early vignette:

Vignette 1

Sam is sitting on the carpet, leaning on several children, they are talking to each other and Sam appears to be listening, his mouth is open, his eyes are rolled back to the top left and his “good ear” is facing in the direction of the conversation. He appears to be concentrating. Every now and again, when the children get excited and laugh Sam twitches suddenly and his gaze moves – his eyes dart in the general direction of the noisy children and then roll back again. “Buggabuggabuggabugga!!!” Sam shouts out loud and wiggles his legs and claps his hands. He now appears excited...

The purpose of writing vignettes was not to convey an accurate and objective truth, but rather to offer a rich, thick, descriptive piece of writing constructed out of the interplay between Sam’s interactions with his world and the researcher’s interpretation. For methodological and ethical reasons it was important to locate understandings in the written text as this was discussed with significant others in order to avoid potentially misrepresenting Sam. The vignettes were read by others who knew Sam or who observed the event, and they offered their own interpretation through informal conversations between lessons or in the playground - which were essential to help deepen understanding of the observations.

Hundreds of vignettes were written and, through this on-going member-checking process, the researcher learned to “see” Sam from the perspectives of others who worked with him. However, this process of interpretation operated bi-directionally insofar as interpretations presented to staff challenged their preconceptions which led them to reconsider and reconstruct their understandings (e.g. whether Sam’s self-directed behaviours were in fact communicative and thus also other-directed). Staff at Sam’s special school originally considered self-directed behaviours to be stereotyped and void of communicative intent; whereas staff at his mainstream school considered the behaviours to be communicative. These different interpretations of behaviours were not simply subjective since they were grounded in observations of Sam in context. Instead, these differences suggested that Sam employed the same behaviours in different contexts for different purposes. Compare vignette 2 to vignette 3 (below). Both of these vignettes capture Sam’s self-directional behaviours, but through rich contextualisation these behaviours take on different significance.

Vignette 2

Sam has just been strapped to his stander (a wooden frame used to support standing and improve posture). A tray is bolted to the stander and Sam is wheeled to the centre of the classroom where the other children are “standing”. The children form a circle with the teacher in the middle. Sam is looking bored. He licks his bottom lip, rolls his eyes back and shows the whites of his eyes. He shakes his head left and right repeatedly. He stops, curls up his top lip and exposes his teeth, frowns and vocalises unhappy sounds (“...uuuurgh!”) whilst looking up at the ceiling. LSAs [learning support assistants] place switches on the trays of each child. The teacher sings the “Good morning song” and calls the name of the child who is meant to press the switch at the end of each verse. The switch emits the pre-recorded phrase: “Good morning, everyone!” Sam becomes increasingly impatient. He flaps his arms like a bird. He then starts to slap the side of his face, pinches his neck, and pulls his hair. He pushes the switch off the table and it crashes to the floor. Over time his self-stimulation becomes notably self-injurious, with red marks appearing on his face and neck where he is hitting and pinching himself. An LSA restrains Sam by holding his arms apart whilst talking gently to him. It looks like Sam is fighting the LSA - his movements are centripetal and it is as if Sam is repeatedly trying to hit himself against the will of the LSA. Eventually, it is Sam’s turn to say “good morning” and press his switch. The LSA gently moves both of Sam’s hands over the switch and presses down. The message is played and the teacher enthusiastically wishes Sam “good morning”. She makes eye contact, smiles then nods and praises Sam. The LSA lets go of Sam’s hands and encourages Sam to hit the switch. Sam pauses. The adults wait in anticipation. Several seconds go by. Sam suddenly pushes the switch off the table and slaps himself in the face.

Here Sam is engaged in what the researcher (and the special school staff) identified as self-injurious behaviour. Red marks appear on Sam’s skin and an LSA holds Sam’s arms to prevent him striking his face again. Sam is averse to the situation and does not engage as the staff would like him to (i.e. by pressing the microswitch). Compare the actions above to those below:

Vignette 3

Sam is sat on his artificial grass mat on the carpet for registration. [...] One of Sam's neighbours stands up, walks over to a yellow box in the corner near the teacher, pulls out his switch and returns to the carpet. She tells Sam to press his "blue button" and smiles. Sam leans forward. The girl takes Sam's hand and places it on top of the switch. The switch is activated and emits a pre-recorded "Good morning!" message. Sam repeatedly hits the switch with both hands (he raises his hands, then suddenly slaps the switch held in front of him, lets his hands fall on his lap, and repeats several times). Sam presses the switch before the recorded message has ended, resulting in the first half of the message being played, over and over. Between each switch-press Sam flaps his arms like a bird whilst smiling and vocalises ("Ooooooh!!!"). He wiggles his legs outstretched in front of him and hits the floor with the back of his heels. He slaps his head with both hands and makes happy sounds. An LSA walks over to Sam and the girl gives the LSA the switch. The LSA crosses Sam's legs, makes him sit up straight, and walks away.

In vignette 3 Sam executes similar behaviours described in vignette 2, but the meaning of these behaviours appears to shift. Sam still flaps his arms and slaps his head, but the rich contextualisation of these behaviours supports a new reading - the actions do not appear to hurt Sam but are part of a repertoire which expresses his happiness. Instead of avoiding pressing the microswitch, he repeatedly presses it with glee. By comparing and contrasting the vignettes in this way the difficulty of ascribing meaning to behaviour without its contextualisation is revealed. What also emerges is the realisation that whilst Sam's special school staff knew Sam intimately; their understandings of him were constrained in that they had only ever observed him in the special school setting. By giving Sam opportunities to engage with other environments such as mainstream school classrooms, and by observing how he responds, preconceptions of him are challenged and he "speaks" in new ways. It is this "speaking" which became a point of debate between the researcher and Sam's special school and mainstream school staff and resulted in staff questioning the researcher's interpretation of the situation as well as their own. This led to on-going, reflective dialogue and more critical thinking around observations of events. Whilst still maintaining that Sam's behaviours could be self-harming, stereotypic and non-communicative, the special school staff began to differentiate between different intensities of self-directed behaviours - those that resulted in red marks were clearly more harmful than those which were gentle. Later, these behaviours were further considered to

be potentially communicative as the correlation between the researcher's presence and Sam's non-harming head-slapping became evident.

- **Behaviour states**

Drawing from Trevarthen and Aitken's (2001) work into the emergence of social awareness in infants, the research sought to better understand if Sam experienced what was labelled "primary intersubjectivity" and "secondary intersubjectivity" (p. 5). Primary intersubjectivity is defined as a rudimentary awareness of the subjectivity of others which is played out during intimate social interactions. These "protoconversations" (*Ibid*, p. 4) involve "gentle, intimate, affectionate, and rhythmically regulated playful exchanges" (*Ibid*, p. 6) and include mimicking facial expressions and vocalisations, turn-taking and anticipation of other's responses. Secondary intersubjectivity is a more sophisticated social awareness in which infants and carers jointly attend to their environment, evidenced through sharing of objects. Understandings were also drawn from research which compared the behaviour states (or levels of alertness) of children with PMLD in different contexts (Foreman et al., 2004). The description of Sam's behaviour states in Table 1 presents a rough approximation of these concepts - (alertness and social engagement) but the detail relating to the meaning and description of behaviour emerged over time after working with Sam and school staff.

At the beginning of the project, the researcher wanted to differentiate between Sam's emotional states. Researchers in the PMLD field have traditionally made use of normative descriptions of expressive behaviour - for example, signs of happiness have been operationalised by research psychologists as facial expressions and vocalisation considered to be indicators of happiness among people without disabilities (such as smiling or laughing) (Green and Reid, 1996). However, as discussed previously, children with PMLD can present in idiosyncratic ways and understanding their behaviours requires familiarity and intimate knowledge. In the same way that a parent may learn to differentiate between the cries of an infant suggesting hunger and cries indicating pain, Sam's school staff developed insights into the different types of self-directed behaviours. This differentiation is illustrated in Table 1: "self-active-unhappy". Learning to recognise these behaviours as expression of a particular emotional state allowed exploration of contextual patterns in the data. Submergence in the data meant that the events described in the vignettes could be compared and contrasted in terms of setting (mainstream school vs. special school), and social partner (special school peers vs. mainstream school peers, adults vs. peers, etc.), leading to confirmation about patterns, which then directed further

exploration. For example, whilst there was no clear relationship between which school Sam attended and his pain, behaviour associated with frustration and boredom was typically associated with his special school activities (such as microswitch tasks).

Behaviour state	Meaning	Description	Context
Passive-unhappy	Bored or not want / not like.	Refuses to move or participate, unhappy noises (e.g., moans), unhappy facial expressions (e.g., frowns).	Mainly in special school.
Passive-distant	Unfocused, 'day dreaming'.	Unfocused eyes ('looking into space'), showing no interest in phenomena around him.	Both special school and mainstream school. Often when tired and hungry, before lunch and near end of day.
Passive-focused	Focused on phenomena.	Keeping still, listening (head tilted so 'good ear' in direction of phenomenon), gaze at ceiling when concentrating, darting in direction of phenomena occasionally.	During lessons designed for sensory experiences in special school and on adults in general. Often on children in mainstream school.
Passive-happy	Enjoying things done to him by others (e.g., massage or physiotherapy).	Happy but not reaching out, happy noises, 'smiley eyes', still, big grins, relaxed.	Adults in mainstream and special school. Children in mainstream school (leaning on them, letting them support his weight during circle time etc.).
Self-active-happy	Self-stimulation.	Exploring himself, happy noises, smiles, exposing and rubbing belly, arching back.	Seen in both settings, but more common in special school.
Other-active-happy	Positively engaged with others. Displaying primary intersubjectivity.	Reaching out, happy vocalisations, eye contact, putting his face close to others, head tilted when listening, very physical, tugging others, putting his legs on others lap, etc., vocalisations: 'ooohwaaah', 'buggabuggabugga', giggles, initiation and maintaining social interaction.	Very rare with peers in special school, sometimes with adults. Mainstream school – frequently with children and often with adults. Behaves in this manner much more in mainstream school than special school.
Self-active-unhappy	Pain / frustration / bored.	Self-harming. Sudden high pitch scream, 'real tears', frantic slapping and hitting (when in pain), progressively hitting side of head and pinching back of neck harder and faster (boredom and frustration).	Seen in both settings, but mostly in special school where behaviour is much more intense.
Other-active-unhappy	Pain / frustration / bored and expressing it to others.	Very rare. Hitting others, pushing them away, trying to communicate discomfort. Pulling hair and not letting go, tears, etc.	Occasionally in both settings.
Object-exploration	Exploring objects.	Exploring object with fingertips, or mouth (chewing, tasting), occasionally visually.	Both special school and mainstream school.
Object-awareness	Understanding purpose of object/object has meaning for Sam.	Use of object for intended purpose (i.e., attempting to use door handles) or use of object in a way which is meaningful for Sam.	Both special school and mainstream school. Wider selection of items in mainstream school.
Other-object-awareness	Sharing object with other person.	Interacting with object and person at same time.	Both settings. Only really food-as-object orientation in

	Secondary intersubjectivity.	Predicting/anticipating response of individual with object. Focused gaze between object and person.	special school. Various additional items in mainstreams school (e.g., balls, bucket and spade, toys, clothes, books)
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Whilst the construction of the behaviour state table provided a lens to interpret Sam's behaviour and look for patterns in the data corpus, it was always important to contextualise these behaviours, to identify shifts in behaviour over time, and to engage in on-going dialogue with others about the meanings of such shifts.

Concluding thoughts

The methodology described breaks away from conventional patterns of conducting research in the PMLD field by emphasising relational forms of knowing, longitudinal qualitative observations, and informal but on-going reciprocal dialogue over the meaning of observed behaviours. The aim in presenting this methodology is to highlight how it guided interpretation of the meaning of Sam's actions. What becomes apparent is that "knowing" Sam required opportunities for him to participate in alternative social milieus which allowed him to express himself differently, thus enriching understandings of his abilities. If voice is situated in the sense that how Sam can "speak" depends on the relationships he has with others across different contexts (e.g. special school vs. mainstream school, peers vs. adults) then individualistic approaches are limited in the extent to which they can capture Sam's voice. Post-positivist and constructivist approaches to research in the PMLD field were identified in the paper. What these approaches have in common is an individualist perspective of children with PMLD. Such work takes a monadic view of children because the focus is on individuals abstracted from the everyday situations and relationships. By contrast the methodology employed here focuses on voice not as singular and literal, but as something that is enacted or comes into being through relationships. Voice is a performance between Sam and his social and material world which unfolds in context. Sensitive observation and co-constructed interpretation of this performance allows Sam to talk in ways that escape objective behavioural observation schedules or constructivist "interview" formats. Yet, at the same time caution is required not to privilege the researcher's interpretation of the situation - the role of others in co-constructing the interpretation of Sam's behaviours is essential. The vignettes aide this process by allowing significant others to critique the interpretation of behaviours contained in the vignettes.

Importantly, this multi-faceted approach to interpretation is something striven for, but is a never-ending process of participation and negotiation.

Finally, whilst this paper has implications for PMLD researchers, insights can also be drawn for practitioners. Practitioners who work together can develop richer understandings over time of the abilities of children with PMLD. Whilst this is likely to be happening in some schools, it is not clear whether this collaboration involves different types of professionals sharing insights and interpretations from observations in different spaces. Sam's special school and mainstream school staff worked with Sam over time to develop insights about his actions. To say that one group of staff has a "true" interpretation is perhaps to miss the point - it was discussion about these differences which led to renewed critical discussions about interpretation, which can only be a positive thing and holds promise for more inclusive practice with children who have PMLD.

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